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An overview of assistive technology for persons with multiple sclerosis

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Abstract—Multiple sclerosis (MS) is a progressive neurologic disease clinically characterized by episodes of focal disorder of the cranial nerves, spinal cord, and the brain. MS affects a significant number of young adults, and they most often face a future of progressive functional losses as more of their central nervous system and cranial nerves are affected. As the disease progresses, they have new impairments with accompanying limitations in activities, restrictions to their participation in life, and compromised quality of life. Assistive technology includes any item that is used to maintain or improve functional capabilities. The rehabilitation healthcare provider has many opportunities to intervene with assistive technologies to decrease activity limitations and participation restrictions. The purpose of this article is to (1) review the impairments and associated activity limitations and participations restrictions experienced by persons with MS, (2) provide an overview of high- and low-tech assistive technologies appropriate for persons with MS, (3) discuss funding opportunities for assistive technologies, (4) review current studies of assistive technology used for persons with MS and discuss future research directions, and (5) consider assistive technology as an intervention for disability prevention.

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INTRODUCTION

Multiple sclerosis (MS) is a progressive neurologic disease clinically characterized by episodes of focal disorder of the cranial nerves, spinal cord, and the brain. Prevalence of MS is less than 1 per 100,000 in equatorial areas; 6 to 14 per 100,000 in the southern United States and southern Europe; and 30 to 80 per 100,000 in Canada, northern Europe, and the northern United States. In 1992, the United States had an estimated 250,000 to 350,000 cases of physician-diagnosed MS (1). Life expectancy is not significantly reduced in the majority of persons with MS, but severe disability is noted in 10 percent within 5 years, in 25 percent within 10 years, and in 50 percent within 18 years (2,3). MS is the third most common cause of disabling illness in individuals between the ages of 15 and 50, with the mean age of onset at 32 years of age. The incidence of MS in children is low with only 0.3 to 0.4 percent of all cases occurring in the first decade of life (4,5). Thus, MS affects a significant number of young adults, and they most often face a future of progressive functional losses as more areas of their central nervous system and cranial nerves are affected. As the disease progresses, they have new impairments with accompanying limitations in activities, restrictions to their participation in life, and compromised quality of life.

Prevalence data reveal that the disease of MS causes activity limitation in 69.4 percent of persons with the disease (6). Recent studies support that elderly persons with MS also experience physical and psychosocial impairments that limit mobility, ability to use public transportation, and ability to complete self-care activities. They also face compromised quality of life, with suicidal thoughts and depressed moods (7).

CONCEPT OF DISABILITY

Disability itself is not always precise and quantifiable. The concept of disability itself is not agreed upon by persons who consider themselves to have a disability, professionals who study disability, or the general public (8). This lack of agreement is an obstacle to all studies of disability and to the equitable and effective administration of programs and policies intended for people with disabilities (8–12). To facilitate agreement about the concept of disability, the World Health Organization (WHO) has developed a global common health language—one that is understood to include physical, mental, and social well-being. The WHO first published the International Classification of Impairment, Disabilities, and Handicaps (ICIDH) in 1980 as a tool for classification of the "consequences of disease." The newest version, International Classification of Functioning, Disability and Health, known as ICF, like its most recent predecessor ICIDH-2, moves away from a "consequence of disease" classification (1980 version) to a "components of health" classification. This latest model is designed to provide a common framework and language for the description of health domains and health-related domains. Using the common language of ICF can help us as healthcare professionals to define the need for healthcare and related services, such as the provision of assistive technology (AT), for persons with diseases that affect them at all levels (13).

In the context of health, the following language is used:

- *Body functions* are the physiological functions of body systems (including psychological functions).
- *Body structures* are anatomical parts of the body, such as organs, limbs, and their components.
- *Impairments* are problems in body function or structure, such as a significant deviation or loss.
- *Activity* is the execution of a task or action by an individual.
- *Participation* is involvement in a life situation.
- *Activity limitations* are difficulties an individual may have in executing activities.
- *Participation restrictions* are problems an individual may experience in involvement in life situations.
- *Environmental factors* make up the physical, social, and attitudinal environments in which people live and conduct their lives (13).

Application of the WHO global common health language will make possible the definition of the need for healthcare and related services; make possible the definition of health outcomes in terms of body, person, and social functioning; provide a common framework for research, clinical work, and social policy; ensure the cost-effective provision and management of healthcare and related services; and characterize physical, mental, social, economic, or environmental interventions that will improve lives and levels of functioning. Provision of AT for persons with MS is an intervention that has the potential to diminish activity limitations and participation restrictions, and in turn, improve quality of life in the face of a disease that progressively produces new impairments. Throughout this discussion of AT and MS, we will use the WHO common health language to discuss the dimensions of health and the potential impact of appropriate AT.

IMPAIRMENTS, POTENTIAL ACTIVITY LIMITATIONS, AND PARTICIPATION RESTRICTIONS

There are constellations of impairments seen during a lifetime with MS. With the MS disease process affecting the cranial nerves, the spinal cord, and the brain, these neurological structures support as many possibilities of impairments as they do functions.

Cranial nerve involvement can produce a wide range of impairments. Optic neuritis with central scotoma produces a loss of vision. Weakness and poor coordination of eye muscles produces double vision. Trigeminal neuralgia (a severe stabbing facial pain) may become chronic and disabling. There can be facial weakness and/or facial myokymia. Involvement of the vestibular nerve can produce vertigo and/or dizziness, and involvement of the auditory nerve can cause hearing loss. There are changes

in the quality of voice with vocal cord weakness as well as dysphagia. Sensation may be altered on the face and taste sensation altered on the tongue. Weakness of the sternocleidomastoid and trapezius can be seen with accessory nerve involvement. Motor function of the tongue may be impaired resulting in dysphagia and dysarthria (14,15).

Brain and spinal cord involvement can result in many other impairments, including:

- Ataxia and tremor.
- Cognitive impairments.
- Double vision.
- Dysarthria.
- Dysphagia.
- Fatigue.
- Hearing loss.
- Heat intolerance.
- Incoordination.
- Lhermitte's Sign (forward flexion of the head produces "electric-shock feeling" in the back and/or limbs).
- Loss of vision.
- Neurogenic bladder.
- Neurogenic bowel.
- Nystagmus.
- Pain.
- Psychiatric impairments and affective disorders.
- Seizures.
- Sensory impairment and paresthesias.
- Sexual dysfunction.
- Spasticity.
- Trigeminal neuralgia.
- Vertigo and dizziness.
- Weakness and paralysis.

Each impairment has the potential to limit activity and restrict participation. For example, double vision may limit reading or driving, which, in turn, may result in a vocational participation restriction. Weakness of legs may result in the inability to walk and climb stairs, which may limit one's ability to continue to live in a home with stairs and interfere with one's ability to participate in recreational activities, such as basketball or jogging. Restriction of participation in decision making at home or at work and danger in being left home alone may be the consequences of cognitive impairments.

QUALITY OF LIFE

These impairments not only limit activity and restrict participation, but also impact the overall quality of life for persons with MS. Quality-of-life issues have been studied from several perspectives. Studies have shown deficits in planning ability and slowed information-processing speed to be characteristic of depressed persons with MS (16). Visual impairment is strongly related to overall health-related quality of life (17). Sexual and bladder problems also have been associated with marked reduction in quality of life (18). The rehabilitation healthcare provider is responsible for applying appropriate interventions to maximize function, therefore, improving the person's activity and his or her involvement in life events. Functioning and disablement are outcomes of interactions between health conditions (MS) and conceptual factors (social, environmental, and personal). The rehabilitation healthcare provider has many opportunities to intervene to decrease activity limitations and participation restrictions. Provision of AT can ameliorate function in the face of a stable or worsening impairment as well as restore environmental and social factors (see **Appendix A**, a case study).

ASSISTIVE TECHNOLOGY

The Technology Related Assistance Act for People with Disabilities of 1988 (Public Law 100–407) defined AT as "any item, piece of equipment, or product system, whether acquired commercially off-the-shelf, modified, or customized, that is used to increase, maintain, or improve functional capabilities of individuals with disabilities." Easily recognized AT devices include items such as walkers, manual wheelchairs, grab bars, researchers, and other aids for daily living. These types of durable medical equipment are readily seen as valuable by the medical profession for individuals and their families struggling to cope with this debilitating disease.

In a recently published study completed for the Multiple Sclerosis Society of Canada, 427 respondents participated in a survey project designed to describe the types of AT devices in their possession and to identify the factors that best predicted the probability of their possession of these devices (19). Sixty-one percent of the respondents (n = 261) reported possession of a manual wheelchair, fifty percent owned grab bars, and forty-four

percent used other mobility aids. Other items owned by the group included walkers (39 percent), bathtub modifications (22 percent), scooters (15 percent), and lifts (14 percent). Other types of reported AT devices included toilet modifications (14 percent), electric wheelchairs (8 percent), orthotics (7 percent), bedroom (7 percent) and vehicle modifications (4.9 percent), and visual aids (4.7 percent). Less then 4 percent of the group possessed cushions, stair ramps, communication aids, or air conditioners.

However, the definition of AT covers a much broader spectrum of devices than those typically prescribed (durable medical equipment) for individuals with MS. AT includes any item that is used to maintain or improve functional capabilities. As such, it can include items such as jar openers for individuals struggling to remove a lid from a stubborn container; pencil grips; alarm signaling devices; large dialers on the telephone; prompting devices for individuals with memory impairments; screen readers for computers; and environmental control systems that open and close doors and drapes, raise and lower beds, or operate electronic devices such as televisions and stereo systems. AT includes both low- and high-tech solutions. Many view AT as being cost prohibitive and inaccessible when it can actually include very low-cost, readily available device, such as the pencil grip just mentioned.

The definition of AT first provided in the Technology Related Assistance for Individuals with Disabilities Act (1988) also included "any service that directly assists an individual with a disability in the selection, acquisition, or use of an AT device, such as—

- Evaluation of the needs of an individual.
- Purchase, lease, or other acquisition of devices.
- Selection, design, fit, customization, adaptation, application, maintenance, repair, or replacement of devices.
- Coordination and use of other therapies, interventions, or services.
- Training or technical assistance for individuals with disabilities and their families as appropriate.
- Training or technical assistance for professionals, employers, and other providers."

The rationale for providing a service component to this definition included the recognition that few professionals, persons with disabilities, their families, or other interested individuals had received comprehensive training in the use and application of AT. It also supported the need to involve any number of individuals (physiatrists, occupational and physical therapists, speech-language pathologists, rehabilitation engineers, family members, computer programmers, case managers, etc.) in the selection process to ensure the appropriate device has been chosen both by and for the end user. Finally, this definition also recognizes the need to provide training and support to professionals, employers, and other providers who interact directly with the person with a disability (Congressional testimony, 1988).

A review of the literature confirms a paucity of research exists in AT and MS (19–21). The study described previously by Finlayson et al. provided the largest population sample found during our search (19). Case studies focusing on interventions during midcourse and end-stage aspects of the disease highlighted the need for proper seating and positioning, as well as for providing augmentative communication devices to support individuals with communication limitations secondary to MS (22,23). Unfortunately, in both of these case studies, the researchers reported little or no follow-up was done once the recommended equipment and/or intervention strategies were provided. This supports the need to incorporate the "service" component of the AT definition. In another article concentrating on the communication needs of those with acquired communication disorders because of MS, the authors supported the need that individuals with communication must be effective consumers of the choices that are offered to them. In addition, Beukelman and Yorkston identified other factors that impact implementing AT for persons with MS. Depending on the age, family status, and occupational choice, individuals with acquired disabilities are surrounded by family members, employers, peers, and others who are also affected by the disorder. Everyone is required to move toward acceptance of a disorder that affects so many aspects of their lives, including the acceptance of assistive devices to facilitate function (24). Although these studies point to the importance of AT as one component of the intervention process, a limited amount of information remains relative to cost benefit analysis of AT, outcomes measurements, and adequate and standardized assessment processes.

AT TO DECREASE OR ELIMINATE ACTIVITY LIMITATIONS AND PARTICIPATION RESTRICTIONS

MS can interfere with life's most basic activities. Driving to the store to buy milk, signing a child's report card, talking to a spouse on the phone or in person, throwing a ball, and dealing with end-of-life issues are all activities perceived to be necessary to our lives. With the onset of MS, however, participation often becomes a thing of the past. While assistive devices will never replace the ease of human functioning, they can and do offer alternative strategies for accomplishing many of life's tasks (see **Appendix A**, a case study). So what are a few of the available AT options for persons with MS?

For persons experiencing visual impairments, a number of AT devices can prove useful. An eye patch to accommodate for double vision (properly prescribed), colored overheads available in a wide array of colors (yellow, blue, green, and red) placed over black-on-white text to help with perception, audiotaped books, and documents and highlighter tape (available at most office stores) can prove extremely useful. Large-print documents, off-white paper, magnifiers and prism glasses, and screen magnification and screen reader software designed to enlarge and/or read aloud text on the computer screen are also available.

Often, simple adaptations such as using nonglare paper can mean the difference between whether or not someone is able to read notes and letters from friends, creating a grocery list without visual fatigue, or remaining focused on the job. For persons who have difficulty reading 10- to 12-point font, simply increasing the font size and choosing Verdana (available on Microsoft Word font type) can decrease visual fatigue. In some situations where individuals have low vision, additional lighting may increase their ability to perform visual tasks such as working on the computer, desk work, and reading.

For those with an acquired hearing loss, hearing aids are often provided. In addition, amplification systems are designed to work in offices, classrooms, and other environments where a number of persons are speaking at once or where the noise level in the environment makes discriminating individual speakers difficult (FM systems, Conference Mate). Low-tech strategies such as asking speakers to move away from windows where lighting obscures facial features, positioning oneself in the front row, or moving to a quieter environment can be suggested to the individual with MS as well as their caregivers and friends.

For cognitive impairments, which limit memory or information processing, a number of new technologies are rapidly being developed. The PocketCoach (AbleLink Technologies, Inc.) is one such device. Designed to function on commercially available personal digital assistants (PDAs), such as the Palm Pilot, Casio, etc., this software provides an auditory prompting feature to assist individuals to remember "what comes next." These products are designed to facilitate memory recall and steps to be taken during individual activities and to provide reminders about daily activities.

Other PDA technologies provide built-in alarm systems to remind persons when it is time to take medication, change activities, or call their significant other. In addition, these systems contain recording features that allow their users to digitally record reminders, activities, and important notes. Standard PDA systems, frequently called "Executive Organizers," are readily available at many office supply stores. Radio Shack, Office Max, and Office Depot usually carry a broad array of electronic organizers. A low-tech solution could include writing on paper the day's schedule or setting an alarm watch (beep or vibrating) to remind the individual that it is time to do something else.

A number of assistive devices designed are available for individuals with upper-body mobility impairments and self-care limitations. Aids for daily living, such as scoop plates, weighted utensils, etc., are readily available and recognized as useful for persons with disabilities. However, many other assistive technologies are available that are frequently overlooked. These are not as well known to providers and the public because of regional preferences, limited marketing, and lack of access product information and/or training.

Simple low-tech examples might include "clippies," commonly used to seal potato chip bags, etc. These inexpensive devices can be extremely useful for individuals struggling to hold a book open to a certain page or to keep documents together. Inexpensive foam curlers can be used as grips for toothbrushes, pencils, and other small tubular items. They come in a variety of sizes and are inexpensive and disposable.

Other assistive devices might include a copyholder placed next to the computer to assist not only with upper-limb impairments but also with visual tracking for persons with MS. Keyguards (Plexiglas boards with

holes drilled for each key on the computer) can help isolate individual keys on the keyboard or prevent activation of unnecessary keystrokes.

Alternate keyboards, such as the IntelliKeys (IntelliTools, Inc.), BigKeys, etc., can provide a larger key surface as well as visual contrast for persons wishing to continue to use the computer. Onscreen keyboards (software-driven) that can be activated by any number of switches, including those activated by hands, feet, eye-gaze, breath support (sip-n-puff), head movement, etc., or any other available movements of the individual, are also available from a number of manufacturers.

Computer-based technologies designed to enable an individual with MS to continue to work, learn, and create may be crucial during the course of this disease. Computer-based technologies can maintain the person with MS in the workplace so that they will continue to receive a paycheck for as long as possible. These technologies can also help maintain relationships with family members and friends via the telephone and Internet, handle daily finances, and communicate end-of-life decisions, all of which are important to the quality of life.

Other activities of daily living aids might include a pull cart to transport groceries or other items, electric page turners, lever handles on doors, key grips designed to provide a larger surface for door keys, door knob grips, or a backpack for carrying difficult items. A number of augmentative and alternative communication (AAC) devices also are available for persons who are unable to talk secondary to MS. These devices run the gamut from simple low-cost, low-tech alphabet, word, phrase, and sentence boards to high-tech voice output devices. Each individual approaches the acquisition of a communication device from his or her own perspective. For many adults and their family members, acceptance of an AAC device may require much support and understanding from the rehabilitation specialist (25).

Electronic voice output devices can be roughly divided into two broad categories—digital and synthetic. Digital systems are usually simple to set up and operate and cost much less than the high-end synthetic devices. These systems act much like a tape recorder, requiring another person to record their voice into the device. Benefits of the digital systems include their (typically) low cost, ease of use, and portability. Limitations include the need to predict what the end user might wish to say and to record it for them in advance, as well as the limited memory system of many of the digital devices.

Synthetic (or text-to-speech) devices are typically much more sophisticated and expensive then the digital systems. Most of the synthetic devices use the DecTalk synthesizer that is intelligible. However, the voice quality does not replace the natural voice quality of the person who is using it. The text-to-speech devices (LightWriter, Dynavox, Pathfinder, and others) can store thousands of words, phrases, and sentences. Like some of the digital systems, these AAC devices can switch from direct selection (using a finger or pointing device) to activate retrieval to a scanning method, which allows the end users to select what they want to say by using a switch. For individuals with MS, having a single device with which they can learn to use and become comfortable and that adjusts to the continuum of their disability is a high priority.

While AT traditionally includes the prescription and implementation of devices for sensory augmentation (speech, hearing, vision, etc.), in recent years, the concept of AT has been broadened to encompass any technology that can improve a person's function (26). This is an important distinction, since it places nonoperative rehabilitation interventions such as orthotics, prosthetics, electrical stimulation, functional neuromuscular stimulation, etc., in the realm of AT (see **Appendix B**).

Assistive Technology Specialist

The application of technology to improve human function has long been the goal of the AT professional. In many cases, clinicians working in AT have been the most successful at crossing traditional clinical boundaries to reach out to their partners unfamiliar with AT, producing collaborations that are both innovative and productive. The AT specialist has the hands-on clinical experience to see what works, and he or she understands those factors leading to technology abandonment. Typical clinical practice, however, does not lend itself to the development of experimental methodologies by clinicians to objectively evaluate subject performance with AT devices and services. Moreover, most AT clinicians do not have the resources to actively participate in a sustained program of research, and these behaviors are not emphasized as a component of clinical intervention in most preservice programs.

Despite this limitation, AT professionals and the AT service delivery model have been effective in getting technology into the hands of the people who need it, creating a foundation for rehabilitation intervention service

delivery in general. Because AT specialists function across disciplines, they are often the first to notice the impact of other treatment modalities. For example, it is typical for adults with an acquired disability to enter rehabilitation services with a variety of needs and to be assigned to various disciplines for treatment. Often, the AT specialist notices incompatibilities. For example, a seating system and a poorly positioned lap tray may create problems for the person with MS trying to develop an alternative access method to the computer to complete vocational tasks.

Funding for Assistive Technology

One of the biggest obstacles to the use of AT by any person with a progressive disease with changing activity limitations and participation restrictions is that of actually acquiring the device. Current funding streams are often difficult to navigate and frequently require a "wait" period to determine eligibility, time that many individuals with MS do not have. For clients and families dealing with this difficult situation, they must meet any number of requirements, typically necessary in written form.

Most third party payers, such as Medicaid and Medicare (Part B supplement), will pay for medically necessary durable medical equipment. This typically does not include items such as computers or assistive devices like many of the ones just mentioned. However, if an assistive device is determined medically necessary (such as using an AAC device to communicate healthcare needs), a case can be made to the provider for coverage. Medicaid eligibility for AT varies from state to state. It is important for professionals working in the field of AT to become familiar with their individual state laws. It is also important for professionals and family members to be aware of the appeals process within their individual state and to use this process when necessary. During the past year, Medicare regulations have been posted that cover AAC devices (http://www.aac-rerc.com/medicare.asp) (26).

Individual benefits for private insurance vary depending on the policy chosen by the purchaser. Like Medicaid, most private insurances will cover some types of durable medical equipment, but often deny coverage for AT devices that are not perceived as medically necessary. In that case, the appeals process should be followed.

For persons eligible for Vocational Rehabilitation (VR) Services, an individual must "be disabled and require VR Services to prepare for, secure, retain or regain employment" (*Id.* § 722(a)(1)). This means any service an individual is to receive from the VR system must be connected to an ultimate employment goal. In Title I of the Rehabilitation Act, the availability of AT devices and services are included in the definition of "rehabilitation technology." Rehabilitation technology is defined as:

> [T]he systematic application of technologies, engineering methodologies, or scientific principles to meet the needs of and address the barriers confronted by individuals with disabilities in areas which include education, rehabilitation, employment, transportation, independent living, and recreation. The term includes rehabilitation engineering, AT devices, and assistive technology services (as defined in the Technology-Related Assistance for Individuals with Disabilities Act of 1988 (Tech Act) (Public Law 100–407).

Veterans are able to obtain assistive technologies through the Veterans Affairs Healthcare system if it is deemed medically necessary. Their healthcare providers working with the Prosthetics Treatment Centers will evaluate both the medical necessity as well as the veteran's eligibility. Special programs are also available to eligible veterans such as the Visual Impairment Services Team, the Housing Improvement and Structural Alterations, and the Automotive Adaptive Equipment Program.

Need for Outcomes Research in Assistive Technology

The study of the impact of AT devices for individuals with MS poses a number of challenges. The field itself is a multidisciplinary area of study that encompasses healthcare; rehabilitation; and psychosocial, educational, engineering, and biotechnology specialties and involves physical, cognitive, psychosocial, sensory, and physiological effects. Consequently, there is a lack of consistency in what has been studied, how the outcomes have been measured, and where the results have been recorded. In the AT field, there is also a paucity of outcomes measurement research in general (27–29).

Persons with functional limitations secondary to MS and with AT devices provided by professionals do not operate in a vacuum. They exist on a broad continuum and are impacted by such things as environmental and psychosocial issues, family finances, cultural differences, and other contextual factors. Services are often fragmented, with many individuals receiving interventions from any number of teams and/or facilities. It is not unusual to hear families talk about their vocational team, hospital team,

and/or any number of private therapists as independent service providers who do not interact. Rarely are discussions held regarding appropriateness of devices across environments, cost effectiveness, or prevention of secondary conditions. In addition, these areas do not have adequate research. It is imperative that rehabilitation and AT specialists work together to develop comprehensive research agendas to demonstrate efficacy of AT devices and intervention services.

Assistive Technology and Disability Prevention

The public health model of prevention defines three categories of prevention: primary, secondary, and tertiary. In persons with disabilities, primary prevention comprises efforts toward preventing a worsening of impairments. For persons with MS, several medications are widely used to affect the natural course of the disease process.

Secondary prevention is aimed at early identification and treatment of a pathological condition and reduction of risk factors for disablement. For persons with MS, many opportunities exist for preventing impairment from limiting one or more activities. Interventions in rehabilitation aimed at the enhancement of activity, such as provision of appropriate AT, can be considered secondary prevention.

Tertiary prevention focuses on arresting the progression of a pathological condition and on limiting further disablement. For people with disabilities, tertiary prevention is designed to limit the restriction of a person's participation in some areas by providing a facilitator or removing a barrier (30). Rehabilitation is traditionally considered a tertiary prevention strategy. Application of AT to reduce environmental and social barriers to participate in life's events is tertiary prevention.

Considering functioning and disablement as outcomes of interactions between health conditions (MS) and conceptual factors (social, environmental, and personal), the rehabilitation healthcare provider has many opportunities to intervene. AT aimed at preventing activity limitations or preventing participation restrictions is a secondary and tertiary prevention strategy that pushes the dynamic model of disablement in the direction of function. The rehabilitation healthcare provider has the responsibility to be actively involved in disability prevention, including assessing and providing AT.

APPENDIX A

CASE STUDY

Sally is a 42-year-old female who presents to her primary care physician with complaints of tingling and numbness in her left foot. This resolves over the next 6 months, but she presents to her physician 18 months later with double vision. Workup and consultation with a neurologist at that time results in a diagnosis of multiple sclerosis. She is placed on disease-modulating medication and educated about lifestyle changes to avoid fatigue, which manages her double vision, with the exception of long workdays. The physician refers her to a vision specialist for management of the impairment of double vision that interferes with activities and participation in her job as an account executive. The physician has also requested the assistive technology specialist to provide information and education about other assistive devices that are available should she develop additional impairments.

A vision specialist recommends an eye patch for use when warranted and suggests she stay in touch with the assistive technology specialist should other problems arise. Two years later, Sally returns to her physician with complaints of weakness and numbness in her right side (upper and lower body). These new impairments interfere with her ability to drive to and from work and chauffeur her children to soccer and other after-school activities. Her function at work has been greatly compromised as well. She is experiencing difficulty with typing, maneuvering around the building, holding her lunch tray, and performing other activities of daily living. She is referred to the physical therapist for an ankle-foot orthosis (AFO) for the right foot and a cane to improve her mobility, and she is referred to the assistive technology specialist for consideration of alternate input methods for the keyboard. A keyboard was chosen that covered a larger surface with large black letters surrounded by a yellow background. Both specialists worked together to identify other aids to facilitate additional activities, such as Sally's personal care activities using a dressing stick and toothbrush handles; cooking using kitchen aids, including jar openers, recipe card holders, and large-handled pots and pans; and gardening using adapted gardening tools.

The physician refers her to a driver's trainer specialist to adapt her vehicle with a spinner knob and left foot accelerator and to train her in this new way of driving. At this time, the physician also referred her to a social worker for support and counseling regarding her finances, work, and personal life decisions.

To date, the assistive technologies have helped Sally to continue to function in her roles as both mother and account executive. She has maintained her income, job status, insurance coverage, and most importantly quality of life.

Six years later, Sally again presents to the physician with severely compromised speech production and difficulty swallowing. This occurred rather rapidly after almost 6 years of a stable course. The physician prescribes a course of steroids. Unfortunately, following this, the impairments remained relatively unchanged. These impairments have resulted in her choosing to leave her job, resign from her duties as room mother, and no longer cheer on the sidelines for her daughters' soccer teams. She has lost 27 pounds to date and appears nutritionally compromised.

At this point, she is referred to a speech language pathologist for a dysphagia evaluation and treatment as well as consideration of an augmentative/alternative communication device (AAC). During these sessions, the assistive technology specialist works with the family and other therapists to select a range of high- and low-tech alternatives for communication. The team works with a nutritional consultant to identify appropriate supplementation.

Throughout the previous 4 years, Sally's family has noticed changes in her memory function. After the psychologist completes a cognitive evaluation and identifies strengths and weaknesses, Sally is provided a hand-held personal digital assistant (PDA), called the "PocketCoach," to aid in her memory skills. This device enables her to push a single button to remember "what to do next." It assists her to remember to complete task activities and to manage important aspects of her healthcare, such as taking medications and nutritional supplements.

Although the course of Sally's disease has been progressive with the development of many new impairments, assistive devices have enabled her to overcome activity limitations and participation restrictions in both her home and job. These assistive devices allowed Sally to actively participate in her home and work life beyond the development of new impairments, supporting a desired quality of life. Even after Sally has had to retire from her job and some of her family responsibilities, she can communicate her healthcare wishes and end-of-life decisions and continue to interact with her family and friends through the help of assistive technology.

APPENDIX B

NATIONAL RESOURCES IN ASSISTIVE TECHNOLOGY

TYPE OF RESOURCE	CONTACT INFORMATION
Funding	**Assistive Technology Funding and Systems Change Project** United Cerebral Palsy Associations Suite 700, 1660 L Street, NW Washington, DC 20036 Contact: Jim Sheldon, Esq. (v) 800-872-5827 (fax) 202-776-0414 (email) atproject@ucpa
	National Assistive Technology Advocacy Project A Project of Neighborhood Legal Services, Inc. Neighborhood Legal Services, Inc. 295 Main Street, Room 495 Buffalo, NY 14203 Contact: Ronald M. Hager, Esq. (v) 716-847-0650 (fax) 716-847-0227 (TDD) 716-847-1322 (email) rhager@nls.org www.nls.org
	National Association of Protection and Advocacy, Inc. 900 Second Street, NE, Suite 211 Washington, DC 20002 (v) 202-408-9514 (fax) 202-408-9520 (email) napas@earthlink.net http://www.protectionandadvocacy.com/napas
Assistive Technology Information	**Technical Assistance Project** 1700 North Moore Street, Suite 1540 Arlington, VA 22209-1903 (v) 703-524-6686 (fax) 703-524-6630 (TDD) 703-524-6639 (email) resnaTA@resna.org http://www.resna.org/taproject/ http://www.ed.gov/offices/OSERS/NIDRR
	RERC for Ergonomic Solutions for Employment University of Michigan, Center for Ergonomics 1205 Beal Avenue Ann Arbor, MI 48109-2117 Director: Thomas J. Armstrong, PhD, Professor, Industrial and Operations Engineering (v) 734-615-2683 (fax) 734-764-3451 http://umrerc.engin.umich.edu/jobdatabase/default.asp

NATIONAL RESOURCES IN ASSISTIVE TECHNOLOGY

TYPE OF RESOURCE	CONTACT INFORMATION
Assistive Technology Information (con't)	**RERC on Wheeled Mobility** University of Pittsburgh School of Health and Rehabilitation Sciences Rehabilitation Science and Technology Pittsburgh, PA 15260 Director: David M. Brienza, PhD; Clifford Brubaker, PhD (v) 412-383-6591 (fax) 412-383-6597 (TTY) 412-383-6598 http://www.rerc.pitt.edu
	RERC on Prosthetics and Orthotics Northwestern University Rehabilitation Engineering Research Program and Prosthetics Research Laboratory 345 East Superior Street Room 1441 Chicago, IL 60611-4496 Director: Dudley S. Childress, PhD, Rehabilitation and Biomedical Engineering (v) 312-238-6524 (fax) 312-238-6510 (TTY) 312-238-6530 http://www.repoc.nwu.edu
	RERC on Assistive Technology for Older Persons with Disabilities State University of New York at Buffalo Center for Assistive Technology 515 Kimball Tower Buffalo, NY 14214 Director: William C. Mann, PhD, Professor (v) 716-829-3141 (v/TTY) 800-628-2281 (fax) 716-829-3217 http://cat.buffalo.edu/rerca.htm
	RERC on Universal Telecommunications Access Trace Center, College of Engineering University of Wisconsin/Madison 5901 Research Park Boulevard, Suite 200 Madison, WI 53710-1252 Director: Gregg C. Vanderheiden, PhD Director: Judith Harkins, PhD (Gallaudet University) (v) 608-263-2309 (fax) 608-262-8848 (TTY) 608-263-5408 http://trace.wisc.edu/telrerc

NATIONAL RESOURCES IN ASSISTIVE TECHNOLOGY

TYPE OF RESOURCE	CONTACT INFORMATION
Assistive Technology Information (con't)	**RERC on Information Technology Access** Trace Research and Development Center University of Wisconsin-Madison 5901 Research Park Boulevard Madison, WI 53719-1252 Director: Gregg C. Vanderheiden, PhD (v) 608-262-2309 (fax) 608-262-8848 (TTY) 608-263-5408 http://trace.wisc.edu/itrerc
	RERC on Communication Enhancement Duke University Department of Surgery Division of Speech Pathology and Audiology Durham, NC 27710 Director: Frank DeRuyter, PhD, Chief, Division of Speech Pathology and Audiology (v) 919-681-9983 (fax) 919-681-9984 (TTY) 919-684-6626 http://www.aac-rerc.com
	Smith-Kettlewell RERC Smith-Kettlewell Eye Research Institute 2318 Fillmore Street San Francisco, CA 94118 Director: John H. Brabyn, PhD (v) 415-345-2110 (fax) 415-345-8455 http://www.ski.org/Rehab
	RERC on Improved Technology Access for Land Mine Survivors Physicians Against Land Mines (PALM) 351 East Huron, Second Floor Annex Chicago, IL 60611 Director: William Kennedy Smith, MD, President, PALM; Dudley S. Childress, PhD (v) 312-926-0030 (fax) 312-926-7662 http://www.banmines.org
	RERC on Hearing Enhancement Gallaudet University Division of Audiology and Speech-Language Pathology Kendall Greene Washington, DC 20002 Director: Matthew H. Bakke, PhD (v/TTY) 718-350-3203 (fax) 718-899-3433 http://www.hearingresearch.org

NATIONAL RESOURCES IN ASSISTIVE TECHNOLOGY

TYPE OF RESOURCE	CONTACT INFORMATION
Assistive Technology Information (con't)	**RERC on Telerehabilitation** Medstar Research Institute National Rehabilitation Hospital 102 Irving Street NW Washington, DC 20010 Director: Michael Rosen, PhD (v) 202-877-1554 (fax) 202-723-0628 http://www.telerehab-nrh.org
	RERC on Universal Design and the Built Environment Department of Architecture Center for Inclusive Design and Environmental Access SUNY/Buffalo Buffalo, NY 14214 Principal Investigator: Ed Steinfeld, ArchD (v) 716-829-3485, ext. 335 (fax) 716-829-3861 http://www.ap.buffalo.edu/~idea
	RERC on Universal Design and the Built Environment Center for Universal Design North Carolina State University Raleigh, NC 27695-8613 Principal Investigator: Molly Story, MS (v/TTY) 800-647-6777 (fax) 919-515-3082 (email) cud@ncsu.edu http://www.design.ncsu.edu/cud
	RERC on Technology Transfer University at Buffalo Center for Assistive Technology 515 Kimball Tower 3435 Main Street Buffalo, NY 14214-3079 Director: Joseph P. Lane, MBPA (v) 716-829-3141 (fax) 716-829-3217 (TTY) 800-628-2281 http://cat.buffalo.edu/ot/cat/rerc-t2.htm
Disability Research and Rehabilitation (including AT)	**National Institute on Disability and Rehabilitation Research** 400 Maryland Avenue, SW Washington, DC 20202-2572 (v) 202-205-8134 (TTY) 202-205-4475 http://www.ed.gov/offices/OSERS/NIDRR/

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